

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Mornington — 29 October 2015

#### Members

Mr Edward O’Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

#### Witnesses

Mr Rory Godbold, and

Ms Tara Szafraniec.

**The CHAIR** — I declare open the Legal and Social Issues Committee inquiry into end-of-life choices. At the outset I would like to thank the Mornington Peninsula Shire Council for accommodating us here at the beautiful Mornington library.

Before I invite you to make some introductory remarks, I caution that all evidence taken at this hearing is protected by parliamentary privilege. You are protected for any comments you make here today but you are not afforded such protection for any comments you make outside the hearing. All evidence is being recorded, and you will be provided with a proof version of the transcript in the next week or so. I would like to welcome Mr Rory Godbold and Ms Tara Szafraniec, who are both appearing in a personal capacity. We have allowed half an hour for our session this morning, so I would invite you to make some opening remarks and thereafter the committee will have questions. Thank you very much for being with us today.

**Ms SZAFRANIEC** — Thank you for inviting us to present today. We really welcome the opportunity to talk to you and be able to tell you our story as well as the story of our dad, Ray Godbold, who passed away on 13 August this year. Since that time we have become more actively engaged in this issue and discussions around end-of-life choices, so thank you for having us here today.

For us, Dad's death was exactly what we had feared. It involved many complications which have had lasting effects on us as his family, and we want to talk to you a bit today about the reality of what we experienced in his final days and give you that personal insight into what happened at the actual coalface for him. As stated in our father's submission — we have written two submissions to the inquiry — and in the *Age* articles about our dad from the last year, he was an experienced palliative care nurse and healthcare professional, and right up until he passed away he was very actively reading and engaging with a whole range of palliative care literature around dying, pain management and cancer.

Dad's wish was to die peacefully at home, and we wanted to help him to achieve this. The week prior to his death, he phoned Rory, myself and Ella to inform us that it was time. He was going to stop his medication and receive morphine and sedative through a syringe driver, and the hope was that over the next few days he would fall asleep and then pass away quite peacefully. This was not the case, and the following days became extremely intense and stressful. Living in country Victoria but only 2 hours from Melbourne, we did not have access to permanent specialist palliative care facilities. Palliative care is managed by the local district nursing services. It is inadequately funded, we believe, and there is an expectation that families, if someone wants to remain at home, deliver the majority of the services — administer drugs and those sorts of things — to the person.

As the days went on, Dad became increasingly distressed, and although he was receiving each day increasingly high doses of morphine he was not relaxed, calm or still, which was quite hard to manage. The visiting district nurse one day phoned the palliative care specialist in Frankston, which was the closest one to us, for advice on his treatment. They advised that they needed to increase sedation — so the midazolam rather than the morphine. This recommendation was delivered at about 9.00 p.m. at night, and because it was after hours, Dad's doctor — the doctor who was coming each day to see him — was not available. The district nurse had to contact the local hospital and speak to the doctor on call to obtain permission to follow the palliative care specialist's advice. We had the sedation medication already at home, but she needed approval before it could be administered. The local doctor on call did not go with the recommendation of the palliative care specialist and instead ordered an oral sedative as an alternative. If the recommendation of the specialist had been followed, we believe the stress over the following 24 hours could have been avoided.

The next day, a week after Dad had been hooked up to the syringe driver, he awoke in the early hours of the morning, at about 5.00 a.m., incredibly breathless and extremely uncomfortable. Watching his skeletal frame struggle to breathe was completely heartbreaking for us. We knew that his death was imminent at this time, and so did he. He asked then, at that point, for the Nembutal. We had worried about not knowing when the best time to take it would have been — and we had had those discussions — but when the right time came, he was not capable of actually swallowing the Nembutal and we would have had to get it for him. If there had been another way, in all honesty we could have helped him to take it or tried at least to help him take it — we do not know what the result would have been, but we do not think anyone would have known either — but we could not do it. He was not able to swallow or eat. Nembutal is very bitter. It is 60 milligrams. We just did not know what the repercussions would be, and we did not want to have to give it to him because we did not know what the repercussions for us would be in terms of criminal issues.

At this point we took Dad to hospital in an ambulance. Upon arriving at the hospital Dad was still in distress, and we explained to the nurses what had been happening. They decided to administer his morphine into multiple places to help facilitate absorption. Due to his weight loss, they believed that his frail body was not absorbing the morphine and sedation. He was six foot and he probably weighed about 40 kilos in the end, and he would not even bruise. He had quite a few falls towards the end, and he did not even bruise because there was no subcutaneous tissue there to actually bruise. Within a few hours of this new approach and increasing the doses of his medication, Dad was finally able to drift off to sleep. For the next 12 hours he was peaceful. He was not able to respond or talk, but finally he was asleep.

Dad had a well-thought-out plan for his death. We were all involved in discussions about how he wanted to go. He did not want us to see him in distress. In saying this, Dad did not want to die, and he fought fiercely right up until the moment, so even though he had the Nembutal and we had talked about it, he still did not want to die. He did not want to leave us. We believe that choice and control are incredibly important no matter how the person dies in the end, and having that in the time leading up to his death is not something that is forced on people. It should be completely voluntary, but you should have the choice to go peacefully in a manner in which you would like to. It is really up to the individual.

Dad publicly accepted the Nembutal on the front page of the *Age* newspaper earlier this year. No-one has followed this up. He was not contacted by the police for doing something quite public that is illegal. This shows that the current laws are not being followed, and Rory is just going to talk about what we believe and think should happen based on our experience.

**Mr GODBOLD** — The things that we have learnt from this experience are that in addition to having been able to access things like Nembutal, physician-assisted deaths are needed to honour people's choices, and this means that it will follow through the choice of the patient and not the moral view of the doctor who decides.

As mentioned, Dad was unable to self-administer the Nembutal, and this was the case beyond a couple of weeks before his death. There need to be numerous options, including intravenous, that can be taken at the right time for the patient. Within a legal framework people can become more empowered to make the decision when the time is right, and only the patient will know when this is. Suffering and trauma may only last a few minutes or hours at the end of someone's life but in those few minutes and hours they should have the choice to avoid that suffering. It should not have to be made months before or weeks before; it should be something that can be made on a minute-by-minute basis so they can go when they are ready.

Secondly, the reported penalties and laws surrounding Nembutal were not enforced, which suggests the laws around that are ineffectual and we need some new laws. Nembutal should be available to everyone, with legislative support, to avoid them ending their lives in traumatic ways for them and their families.

Thirdly, in the end we were not able to keep Dad at home despite the best efforts of palliative care. Many people want to die at home in comfort, and assisted dying would assure that in most cases this could happen. Increasing palliative drugs to lethal doses and terminal sedation reaches the same outcome in the end, but using drugs such as Nembutal would create a comfort, a swiftness and ease to the last stages of someone's life. It is already happening; people are ending their lives in numerous methods, including Nembutal, so it is important that we come up with some strategies to support it for the patients and the doctors.

Lastly, five states in the US, and Belgium and the Netherlands, already have models that we can borrow from and learn from. Death is a fact and people have the right to ask for help and for a choice in how they spend their last few moments in the world.

**The CHAIR** — Thank you both very much for your submission, your father's submission and also for being here today. I suppose I want to get you to talk further about the issue of choice and control and, as you referred to it, Rory, the choice of the patient not the moral view of the doctor. As you see it, the decision of the doctor on duty that night to not go with the recommendation or the wishes of your father was a significant factor in the way things played out.

**Ms SZAFRANIEC** — Yes, that is our belief, that if we had been able to administer the higher doses of sedative that was recommended by the palliative care specialist, we feel that Dad might have achieved that comfort that he could have. The sedative that was recommended was an oral sedative — Rohypnol I think it

was. What we concluded from that is that if we had been able to get that higher dosage of midazolam into his syringe driver, he would have been much more comfortable. Yes.

**Mr GODBOLD** — And it was quite evident that there was not a consistency in the treatment plans for people, as the doctors had very different views on what could happen. Dad's doctor was unable to be contacted about it. We also had quite a few issues in the days leading up around getting dosages right and also faulty equipment. The syringe driver, a couple of times over the days leading up to it, was leaking because it was very delicate, so any major movement would kind of pull it out. Also Dad was on such a large dosage that the syringe driver would not take the full amount, so it was kind of trying to balance out how much they could actually put in it.

In terms of him getting exactly what he needed, there were a couple of factors in that, including that the recommendation was not taken up by the doctor, so it was hard for him to reach comfort because there was no consistency across the decisions that were being made.

**Ms SZAFRANIEC** — It highlighted to us how siloed the different people are in trying to provide some coordinated care.

**Mr GODBOLD** — And how different the beliefs of different doctors can be about this kind of care at the end of people's lives.

**Ms PATTEN** — Thank you very much. You have obviously become far more medically educated over this process.

**Ms SZAFRANIEC** — Yes.

**Ms PATTEN** — You mentioned earlier the services that were lacking for you at home that could have made things easier, and obviously non-faulty equipment would have been one of those. But could you mention any other services that would have been a great help for you in those weeks when your father was staying at home?

**Ms SZAFRANIEC** — I think one of the hard things was that for any breakthrough medication that Dad needed — so the top-ups — Mum had to actually decide when he needed that and then also had to administer that as well. I guess we needed some additional support around that sort of in-between stage. The doctor is only there for a few minutes a day, and then the district nurse would often spend quite a bit of time with us, but that was because Dad was quite complicated. So certainly there could be some additional support in that way in terms of administering medication. I am not sure — —

**Ms PATTEN** — Would that have been a phone call, someone at the end of the phone for your mum or — —

**Ms SZAFRANIEC** — Yes. We did often call up the district nurse. But again a palliative care specialist number or something you could call — and I do not know if it exists to be honest — where you could get that particular advice would be really useful.

**Mr GODBOLD** — The hard thing — and none of us were expecting it, including Dad — was the amount of agitation he experienced. In some cases a phone call to the district nurses or a palliative care specialist would suffice, but because at times he was up out of bed, putting himself in a vulnerable position and falling over, he was quite disoriented. He thought he had to get up and go to work. He was looking for the car keys to get in the car even though he could barely stand up. This kind of state of agitation and distress he was in meant that the breakthroughs were very unpredictable. We were struggling to control him and keep him in bed because of the level of confusion he was experiencing, so that made the breakthroughs all the more hard because you could not plan for it.

**Mr MULINO** — Thanks very much for your submissions and also for your evidence today. One issue that I was interested in was the conversation that you had. It sounds like you were very proactive as a family in discussing your father's wishes. One of the issues we have been thinking about is the extent to which those kinds of conversations should be formalised and people should write it down. I am just wondering, how did you record those wishes, and do you think it is useful to write down the results of those conversations?

**Ms SZAFRANIEC** — I guess because Dad was being so public with his, so he had stuff printed in the *Age*. A lot of it was written down in that sense, but we had not really written down anything more formal, and that may have been potentially useful in hindsight — these are some of the different scenarios that potentially could happen, these are some of the ways they could be handled. But I certainly think it is of benefit, even if people can have facilitated conversations potentially, to write it down and give some kind of consent.

The thing that we have learnt and we have been talking about is just how complicated every death can potentially be and how every scenario is going to be so incredibly different, so how you manage that and start to put a framework and that sort of thing around it is going to be incredibly tricky. We were fortunate that Dad was going public. He was being interviewed, things were being written down, he was talking to Andrew Denton. We were having these amazing conversations with people, who were asking us questions as well, and that was hugely beneficial to us, we felt.

**Mr GODBOLD** — Yes. I think the communication was very open among the family. I think that there probably would need to be some kind of documentation process in place, because even the week before, when Dad said he was going to go off anything that is going to prolong his life and just go on pain management, he said his intention was not to take the Nembutal. But then the day before he died the suffering got so much that he wanted it. It does mean that the lines are never clear cut, so I guess documentation would be needed to support that, especially if communication in families was not as open as it is in ours.

**Ms SZAFRANIEC** — Yes, absolutely.

**Mr MELHEM** — Thank you, and I am really pleased to hear your story. It is a real story. In fact, I was faced with a similar situation two days ago.

**Ms SZAFRANIEC** — I am sorry to hear that.

**Mr MELHEM** — There was no directive or care plan; they have lost it at the hostel for my mother-in-law. But anyway, she is okay now, but it was that close. I know you said your dad wanted to live, and no-one wants to die, of course. I think you said the pill was considered maybe a day or two before, but from your own experience, how do you determine the trigger? I know you talked about the sorts of changes to the law we need to make. You talked about how we need to make sure it is all documented and give that choice. We have talked about other cases where some people might have a mental illness, for example, so physically they are okay but their concern is, ‘I want to take the pill now; I don’t want to live anymore’. That is how they can control that. You did talk about how you want to have choice and control. In your experience — you mentioned paperwork to make sure everyone is covered — but do I understand you correctly that in the last day or two that is what your dad was saying — that his wishes were ‘Give me that pill’?

**Ms SZAFRANIEC** — That is correct. We had had those discussions, and we were worried — when do you know it is the right time to do this? That comes very much into that choice and control. So some people may feel several weeks before that they cannot bear the thought of getting that ill — they might live alone, there might be a whole range of different scenarios — but in our experience Dad wanted to hang on to every single moment. But that morning when he woke up just so distressed, incredibly breathless — he had had a week of being on the sedative, quite lucid moments, quite confused moments — he just knew and we knew as well. I do not know really how to explain it, but he just knew ‘This is the time that I want to be able to go’. That was literally when he was in so much pain. You could tell that the suffering was just beyond anything that we could control at home, and he just knew.

We got him a chair from the lounge room to sit him up, because he had literally been writhing on the floor. We got him the chair, he sat down and he went, ‘Oh, finally’. He told us to get the Nembutal for him, and we had to say no. We had to say, ‘We can’t give it to you, Dad. We don’t know if you can swallow it. We can’t hand it to you’. And he understood; he knew. We had already had the district nurse called, and she had got the ambulance on the way. We were getting too involved in his medication. Mum was being his nurse but also being his wife and all of that sort of thing, so we just knew we had to step back and let some other people take control and take care of him.

**Mr GODBOLD** — There was a distinct moment of change in him when he realised, I think, that he was not going to achieve his peaceful death at home.

**Ms SZAFRANIEC** — Yes.

**Mr GODBOLD** — So his death at home was going to be he was going to asphyxiate. He was very short of breath, and that was really distressing him. I think he thought that that was the way it was going to happen, even though, like everyone, he had expressed he wanted to go to sleep and hopefully just pass away in bed. The moment he realised that that was not going to be achieved was the moment that he asked for the Nembutal.

**Ms SZAFRANIEC** — Yes, exactly.

**Ms PATTEN** — Your father would be so proud of what you are doing at the moment.

**Ms SZAFRANIEC** — Thank you.

**Ms PATTEN** — It is extraordinary, and I am really grateful for what you are doing. I also think that you have probably learnt as much as your father did about all of the choices. In looking at Oregon, where the prescription can be given but obviously the person who has the prescription must take it themselves, versus the Netherlands, where there can be some assistance, what would you recommend that we recommend?

**Ms SZAFRANIEC** — In Dad's case he would have needed assistance to be able to take it, whether that was either us as a family — Mum had been administering all his medications; we had a butterfly syringe thing in his arm. So whether or not we could have helped him get it, potentially he could have pushed the plunger or whatever.

I think we need to look and take some of the best. It needs to be voluntary. In some cases there does need to be assistance. A person can be of sound mind and be able to make that choice but physically incapacitated and so unable to swallow something or be able to put something into their mouth or something. If you know that is their express wish, they should be able to do it. I believe there needs to be multiple options and multiple ways for it to happen. Dad had the Nembutal, but what we learnt from this was that we thought he had a choice and control over this and in the end he did not. We believe there needs to be some variety of options, and that is the stuff that you put down in the written consent or the verbal — you know, there are multiple ways of consenting — so you understand exactly what the person's wishes are.

**Ms PATTEN** — When he got the Nembutal did that change his demeanour, or was he so educated and practised?

**Ms SZAFRANIEC** — I think he was so educated. It definitely did help. Rory, what do you think?

**Mr GODBOLD** — Yes, he described it as his back pocket plan. So it did give him comfort that if it did get to that stage — and with all those deaths he had seen, which had stuck with him — he had his back pocket plan so he could get out of that. But just on the previous point, I believe if we are giving people a choice, we need to be able to honour that choice. I think Nembutal is the first step, because it can be self-administered, but if you are letting people have that choice, then if they get to a stage where they cannot have it, we need a plan B, another kind of back pocket plan for people. That makes it more complex, I think, but if you do give people a choice for the first option, then there needs to be a choice in case they cannot take that first option.

**The CHAIR** — Can I ask one further question? In your father's submission, he talked about being a nurse with 34 years of experience, and you have spoken about how the last four years of his work was with advanced cancer and palliative clients and patients. How much of his experience informed his view on this issue, do you think? Do you want to just talk to that?

**Ms SZAFRANIEC** — It informed his view hugely, because he had seen the good and the bad. He had seen the extreme and the way it happens when it does work out peacefully and perfectly and everyone gets a chance to say goodbye. But he had also seen the protracted, prolonged, drawn-out traumatic deaths that, as someone who was working in that industry and seeing it all the time, completely stuck with him and traumatised him. Then there are the families — they are the ones who are left with the memories and that sort of thing. Also, the thing with Dad is, because he had that experience, he knew the variety of scenarios in terms of the ways in which he could potentially go; and he was very honest and open about that.

I remember sitting down outside, and he would run us through: these are the different options of the ways I can die. He did not want the cancer in his oesophagus — the gastro-oesophageal cancer — to take him. Because he had other metastases in his liver and that sort of thing, he actually wanted those to be the ones that claimed his life; because the gastro-oesophageal cancer, the particular one that he had, almost always ends up in incredibly traumatic death. With his background and his knowledge working within the palliative care system and knowing what the rules, regulations and processes were, his belief was that this can be part of a palliative care process. It does not have to be a completely separate thing that sits on the side; it can be in some way integrated and part of that existing service that is provided.

He had that experience, he had that knowledge and everything that he had seen, you know, his whole life. We ended up saying that this ended up — apart from having us — being what he needed to do. That is where his life led him in the end.

**Mr GODBOLD** — Yes, he nursed so many people and had been with so many people in those final stages, and he did often speak about being at work and being there when that person died. The amount he had seen, I think, is bigger than we can imagine. But one of the things he spoke about was there is physical pain but there is also emotional pain — emotional pain for the person who is dying and emotional pain for the family. I think that really pushed him in the last stages, because he saw this kind of voluntary assisted dying as a way to avoid the emotional pain for the patient and the emotional pain for the family. ‘Existential distress’ was a term that Dad spoke about. That, sure people were having physical pain when they were dying, but he had also witnessed lots of people just crying out in pain that this cannot be the way it is — ‘I can’t go like this’, ‘I’m too young’ and ‘I’ve got all this stuff still to do’.

I think Dad experienced some of that existential distress, so I think his being able to live through so many patients meant that in the end he knew exactly what he was facing up to. I think, like everyone else, he was terrified of it.

**The CHAIR** — Before we close is there anything further you would like to add or like to say?

**Ms SZAFRANIEC** — No. Thank you.

**The CHAIR** — Rory and Tara, thank you both very much for sharing your personal story. We really, really appreciate it.

**Witnesses withdrew.**